

105TH CONGRESS
1ST SESSION

S. 1345

To amend titles XVIII and XIX of the Social Security Act to expand and clarify the requirements regarding advance directives in order to ensure that an individual's health care decisions are complied with, and for other purposes.

IN THE SENATE OF THE UNITED STATES

OCTOBER 30, 1997

Mr. ROCKEFELLER (for himself and Ms. COLLINS) introduced the following bill; which was read twice and referred to the Committee on Finance

A BILL

To amend titles XVIII and XIX of the Social Security Act to expand and clarify the requirements regarding advance directives in order to ensure that an individual's health care decisions are complied with, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Advance Planning and
5 Compassionate Care Act of 1997”.

1 **SEC. 2. EXPANSION OF ADVANCE DIRECTIVES.**

2 (a) MEDICARE.—Section 1866(f) of the Social Secu-
 3 rity Act (42 U.S.C. 1395cc(f)) (as amended by section
 4 4641 of the Balanced Budget Act of 1997 (Public Law
 5 105–33; 111 Stat. 487)) is amended—

6 (1) in paragraph (1)—

7 (A) in subparagraph (B), by inserting
 8 “and if presented by the individual, to include
 9 the content of such advance directive in a
 10 prominent part of such record” before the semi-
 11 colon;

12 (B) in subparagraph (D), by striking
 13 “and” at the end;

14 (C) in subparagraph (E), by striking the
 15 period and inserting “; and”; and

16 (D) by inserting after subparagraph (E)
 17 the following:

18 “(F) to provide each individual with the oppor-
 19 tunity to discuss issues relating to the information
 20 provided to that individual pursuant to subpara-
 21 graph (A) with an appropriately trained profes-
 22 sional.”; and

23 (2) by adding at the end the following:

24 “(4)(A) An advance directive validly executed outside
 25 of the State in which such advance directive is presented
 26 by an adult individual to a provider of services or a pre-

1 paid or eligible organization shall be given the same effect
 2 by that provider or organization as an advance directive
 3 validly executed under the law of the State in which it
 4 is presented would be given effect.

5 “(B) Nothing in this paragraph shall be construed
 6 to authorize the administration, withholding, or with-
 7 drawal of health care unless it is consistent with the laws
 8 of the State in which an advance directive is presented.

9 “(C) The provisions of this paragraph shall preempt
 10 any State law to the extent such law is inconsistent with
 11 such provisions. The provisions of this paragraph shall not
 12 preempt any State law that provides for greater port-
 13 ability, more deference to a patient’s wishes, or more lati-
 14 tude in determining a patient’s wishes.”.

15 (b) MEDICAID.—Section 1902(w) of the Social Secu-
 16 rity Act (42 U.S.C. 1396a(w)) is amended—

17 (1) in paragraph (1)—

18 (A) in subparagraph (B)—

19 (i) by striking “in the individual’s
 20 medical record” and inserting “in a promi-
 21 nent part of the individual’s current medi-
 22 cal record”; and

23 (ii) by inserting “and if presented by
 24 the individual, to include the content of

1 such advance directive in a prominent part
2 of such record” before the semicolon;

3 (B) in subparagraph (D), by striking
4 “and” at the end;

5 (C) in subparagraph (E), by striking the
6 period and inserting “; and”; and

7 (D) by inserting after subparagraph (E)
8 the following:

9 “(F) to provide each individual with the oppor-
10 tunity to discuss issues relating to the information
11 provided to that individual pursuant to subpara-
12 graph (A) with an appropriately trained profes-
13 sional.”; and

14 (2) by adding at the end the following:

15 “(5)(A) An advance directive validly executed outside
16 of the State in which such advance directive is presented
17 by an adult individual to a provider or organization shall
18 be given the same effect by that provider or organization
19 as an advance directive validly executed under the law of
20 the State in which it is presented would be given effect.

21 “(B) Nothing in this paragraph shall be construed
22 to authorize the administration, withholding, or with-
23 drawal of health care otherwise prohibited by the laws of
24 the State in which an advance directive is presented.

1 “(C) The provisions of this paragraph shall preempt
2 any State law to the extent such law is inconsistent with
3 such provisions. The provisions of this paragraph shall not
4 preempt any State law that provides for greater port-
5 ability, more deference to a patient’s wishes, or more lati-
6 tude in determining a patient’s wishes.”.

7 (c) EFFECTIVE DATES.—

8 (1) IN GENERAL.—Subject to paragraph (2),
9 the amendments made by subsections (a) and (b)
10 shall apply to provider agreements entered into, re-
11 newed, or extended under title XVIII of the Social
12 Security Act, and to State plans under title XIX of
13 such Act, on or after such date (not later than 1
14 year after the date of the enactment of this Act) as
15 the Secretary of Health and Human Services speci-
16 fies.

17 (2) EXTENSION OF EFFECTIVE DATE FOR
18 STATE LAW AMENDMENT.—In the case of a State
19 plan under title XIX of the Social Security Act
20 which the Secretary of Health and Human Services
21 determines requires State legislation in order for the
22 plan to meet the additional requirements imposed by
23 the amendments made by subsection (b), the State
24 plan shall not be regarded as failing to comply with
25 the requirements of such title solely on the basis of

1 its failure to meet these additional requirements be-
2 fore the first day of the first calendar quarter begin-
3 ning after the close of the first regular session of the
4 State legislature that begins after the date of the
5 enactment of this Act. For purposes of the previous
6 sentence, in the case of a State that has a 2-year
7 legislative session, each year of the session is consid-
8 ered to be a separate regular session of the State
9 legislature.

10 **SEC. 3. STUDY AND RECOMMENDATIONS TO CONGRESS ON**
11 **ISSUES RELATING TO ADVANCE DIRECTIVE**
12 **EXPANSION.**

13 (a) STUDY.—The Secretary of Health and Human
14 Services shall conduct a thorough study regarding the im-
15 plementation of the amendments made by section 2 of this
16 Act.

17 (b) REPORT.—Not later than 18 months after the
18 date of enactment of this Act, the Secretary of Health and
19 Human Services shall submit a report to Congress that
20 contains a detailed statement of the findings and conclu-
21 sions of the Secretary regarding the study conducted pur-
22 suant to subsection (a), together with the Secretary's rec-
23 ommendations for such legislation and administrative ac-
24 tions as the Secretary considers appropriate.

1 **SEC. 4. STUDY AND LEGISLATIVE PROPOSAL TO CONGRESS.**

2 (a) STUDY.—

3 (1) IN GENERAL.—The Secretary of Health and
4 Human Services shall conduct a thorough study of
5 all matters relating to the creation of a national uni-
6 form policy on advance directives for individuals re-
7 ceiving items and services under titles XVIII and
8 XIX of the Social Security Act (42 U.S.C. 1395 et
9 seq., 1396 et seq.).

10 (2) MATTERS STUDIED.—The matters studied
11 by the Secretary of Health and Human Services
12 shall include issues concerning—

13 (A) the election or refusal of life-sustaining
14 treatment;

15 (B) the provision of adequate palliative
16 care including pain management;

17 (C) the portability of advance directives,
18 including the cases involving the transfer of an
19 individual from one health care setting to an-
20 other;

21 (D) immunity for health care providers
22 that follow the instructions in an individual's
23 advance directive;

24 (E) exemptions for health care providers
25 from following the instructions in an individ-
26 ual's advance directive;

1 (F) conditions under which an advance di-
 2 rective is operative;

3 (G) revocation of an advance directive by
 4 an individual;

5 (H) the criteria for determining that an in-
 6 dividual is in terminal status; and

7 (I) surrogate decision making regarding
 8 end of life care.

9 (b) REPORT TO CONGRESS.—Not later than 1 year
 10 after the date of enactment of this Act, the Secretary of
 11 Health and Human Services shall submit a report to Con-
 12 gress that contains a detailed description of the results
 13 of the study conducted pursuant to subsection (a).

14 (c) CONSULTATION.—In conducting the study and
 15 developing the report under this section, the Secretary of
 16 Health and Human Services shall consult with physicians
 17 and other health care provider groups, consumer groups,
 18 the Uniform Law Commissioners, and other interested
 19 parties.

20 **SEC. 5. DEVELOPMENT OF STANDARDS TO ASSESS END-OF-**
 21 **LIFE CARE.**

22 The Secretary of Health and Human Services,
 23 through the Administrator of the Health Care Financing
 24 Administration, the Director of the National Institutes of
 25 Health, and the Administrator of the Agency for Health

1 Care Policy and Research, shall develop outcome stand-
 2 ards and measures to evaluate the performance of health
 3 care programs and projects that provide end-of-life care
 4 to individuals and the quality of such care.

5 **SEC. 6. NATIONAL INFORMATION HOTLINE FOR END-OF-**
 6 **LIFE DECISIONMAKING.**

7 The Secretary of Health and Human Services,
 8 through the Administrator of the Health Care Financing
 9 Administration, shall establish and operate directly, or by
 10 grant, contract, or interagency agreement, out of funds
 11 otherwise appropriated to the Secretary, a clearinghouse
 12 and 24-hour toll-free telephone hotline, to provide
 13 consumer information about advance directives, as defined
 14 in section 1866(f)(3) of the Social Security Act (42 U.S.C.
 15 1395cc(f)(3)), and end-of-life decisionmaking.

16 **SEC. 7. EVALUATION OF AND DEMONSTRATION PROJECTS**
 17 **FOR INNOVATIVE AND NEW APPROACHES TO**
 18 **END-OF-LIFE CARE FOR MEDICARE BENE-**
 19 **FICIARIES.**

20 (a) DEFINITIONS.—In this section:

21 (1) MEDICARE BENEFICIARIES.—The term
 22 “medicare beneficiaries” means individuals who are
 23 entitled to benefits under part A or eligible for bene-
 24 fits under part B of the medicare program.

1 (2) MEDICARE PROGRAM.—The term “medicare
2 program” means the health care program under title
3 XVIII of the Social Security Act (42 U.S.C. 1395 et
4 seq.).

5 (3) SECRETARY.—The term “Secretary” means
6 the Secretary of Health and Human Services.

7 (b) EVALUATION OF EXISTING PROGRAMS.—

8 (1) IN GENERAL.—The Secretary, through the
9 Administrator of the Health Care Financing Admin-
10 istration, shall conduct ongoing evaluations of inno-
11 vative health care programs that provide end-of-life
12 care to medicare beneficiaries who are seriously ill or
13 who suffer from a medical condition that is likely to
14 be fatal.

15 (2) REQUIREMENTS.—Evaluations conducted
16 under this subsection shall include the following:

17 (A) Evidence that the evaluated program
18 implements practices or procedures that result
19 in improved patient outcomes, resource utiliza-
20 tion, or both.

21 (B) A definition of the population served
22 by the program and a determination as to how
23 accurately that population reflects the total
24 medicare beneficiaries in the area who are in
25 need of services offered by the program.

1 (C) A description of the eligibility require-
2 ments and enrollment procedures for the pro-
3 gram.

4 (D) A detailed description of the services
5 provided to medicare beneficiaries served by the
6 program and the utilization rates for such serv-
7 ices.

8 (E) A description of the structure for the
9 provision of specific services.

10 (F) A detailed accounting of the costs of
11 providing specific services under the program.

12 (G) A description of any procedures for of-
13 fering medicare beneficiaries a choice of services
14 and how the program responds to the pref-
15 erences of the medicare beneficiaries served by
16 the program.

17 (H) An assessment of the quality of care
18 and of the outcomes for medicare beneficiaries
19 and the families of such beneficiaries served by
20 the program.

21 (I) An assessment of any ethical, cultural,
22 or legal concerns regarding the evaluated pro-
23 gram and with the replication of such program
24 in other settings.

1 (J) Identification of any changes to regula-
 2 tions, or of any additional funding, that would
 3 result in more efficient procedures or improved
 4 outcomes, for the program.

5 (3) EXTERNAL EVALUATORS.—The Secretary
 6 shall contract with 1 or more external evaluators to
 7 coordinate and conduct the evaluations required
 8 under this subsection and under subsection (c)(4).

9 (4) USE OF OUTCOME MEASURES AND STAND-
 10 ARDS.—An evaluation conducted under this sub-
 11 section and subsection (c)(4) shall use the outcome
 12 standards and measures required to be developed
 13 under section 5 as soon as those standards and
 14 measures are available.

15 (c) DEMONSTRATION PROJECTS.—

16 (1) AUTHORITY.—The Secretary, through the
 17 Administrator of the Health Care Financing Admin-
 18 istration, shall conduct demonstration projects to de-
 19 velop new and innovative approaches to providing
 20 end-of-life care to medicare beneficiaries who are se-
 21 riously ill or who suffer from a medical condition
 22 that is likely to be fatal.

23 (2) APPLICATION.—Any entity seeking to con-
 24 duct a demonstration project under this subsection

1 shall submit to the Secretary an application in such
2 form and manner as the Secretary may require.

3 (3) SELECTION CRITERIA.—

4 (A) IN GENERAL.—In selecting entities to
5 conduct demonstration projects under this sub-
6 section, the Secretary shall select entities that
7 will allow for demonstration projects to be con-
8 ducted in a variety of States, in an array of
9 care settings, and that reflect—

10 (i) a balance between urban and rural
11 settings;

12 (ii) cultural diversity; and

13 (iii) various modes of medical care
14 and insurance, such as fee-for-service, pre-
15 ferred provider organizations, health main-
16 tenance organizations, hospice care, home
17 care services, long-term care, and inte-
18 grated delivery systems.

19 (B) PREFERENCES.—The Secretary shall
20 give preference to applications for demonstra-
21 tion projects that—

22 (i) will serve medicare beneficiaries
23 who are dying of illnesses that are most
24 prevalent under the medicare program, in-
25 cluding cancer, heart failure, chronic ob-

1 structive respiratory disease, dementia,
2 stroke, and progressive multifactorial frail-
3 ty associated with advanced age; and

4 (ii) appear capable of sustained serv-
5 ice and broad replication at a reasonable
6 cost within commonly available organiza-
7 tional structures.

8 (4) EVALUATIONS.—Each demonstration
9 project conducted under this subsection shall be
10 evaluated at such regular intervals as the Secretary
11 determines are appropriate. An evaluation of a
12 project conducted under this subsection shall include
13 the items described in subsection (b)(2) and the fol-
14 lowing:

15 (A) A comparison of the quality of care
16 and of the outcomes for medicare beneficiaries
17 and the families of such beneficiaries served by
18 the demonstration project to the quality of care
19 and outcomes for such individuals that would
20 have resulted if care had been provided under
21 existing delivery systems.

22 (B) An analysis of how ongoing measures
23 of quality and accountability for improvement
24 and excellence could be incorporated into the
25 demonstration project.

1 (C) A comparison of the costs of the care
2 provided to medicare beneficiaries under the
3 demonstration project to the costs of that care
4 if it had been provided under the medicare pro-
5 gram.

6 (5) WAIVER AUTHORITY.—The Secretary may
7 waive compliance with any requirement of titles XI,
8 XVIII, and XIX of the Social Security Act (42
9 U.S.C. 1301 et seq., 1395 et seq., 1396 et seq.)
10 which, if applied, would prevent a demonstration
11 project carried out under this subsection from effec-
12 tively achieving the purpose of such a project.

13 (d) ANNUAL REPORTS TO CONGRESS.—

14 (1) IN GENERAL.—Beginning 1 year after the
15 date of enactment of this Act, and annually there-
16 after, the Secretary shall submit to Congress a re-
17 port on the quality of end-of-life care under the med-
18 icare program, together with any suggestions for leg-
19 islation to improve the quality of such care under
20 that program.

21 (2) SUMMARY OF RECENT STUDIES.—A report
22 submitted under this subsection shall include a sum-
23 mary of any recent studies and advice from experts
24 in the health care field regarding the ethical, cul-
25 tural, and legal issues that may arise when attempt-

1 ing to improve the health care system to meet the
2 needs of individuals with serious and eventually fatal
3 illnesses.

4 (3) CONTINUATION OR REPLICATION OF DEM-
5 ONSTRATION PROJECTS.—Beginning 3 years after
6 the date of enactment of this Act, the report re-
7 quired under this subsection shall include rec-
8 ommendations regarding whether the demonstration
9 projects conducted under subsection (c) should be
10 continued and whether broad replication of any of
11 those projects should be initiated.

12 (e) FUNDING.—The Secretary shall provide for the
13 transfer from the Federal Hospital Insurance Trust Fund
14 established under section 1817 of the Social Security Act
15 (42 U.S.C. 1395i) of such sums as are necessary for the
16 costs of conducting evaluations under subsection (b), con-
17 ducting demonstration projects under subsection (c), and
18 preparing and submitting the annual reports required
19 under subsection (d). Amounts may be transferred under
20 the preceding sentence without regard to amounts appro-
21 priated in advance in appropriations Acts.

1 **SEC. 8. MEDICARE COVERAGE OF SELF-ADMINISTERED**
2 **MEDICATION FOR CERTAIN PATIENTS WITH**
3 **CHRONIC PAIN.**

4 (a) IN GENERAL.—Section 1861(s)(2) of the Social
5 Security Act (42 U.S.C. 1395x(s)(2)) (as amended by sec-
6 tion 4557 of the Balanced Budget Act (Public Law 105–
7 33; 111 Stat. 463)) is amended—

8 (1) by striking “and” at the end of subpara-
9 graph (S);

10 (2) in subparagraph (T), by striking the period
11 at the end and inserting “; and”; and

12 (3) by inserting after subparagraph (T) the fol-
13 lowing:

14 “(U) self-administered drugs which may be dis-
15 pensed only upon prescription and which are pre-
16 scribed for the relief of chronic pain in patients with
17 a life-threatening disease or condition;”.

18 (b) EFFECTIVE DATE.—The amendments made by
19 subsection (a) shall apply to items and services furnished
20 on or after June 1, 1998.

○